



Foundation for PSP | CBD and Related Brain Diseases

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SUPPORT NETWORK LOCATIONS

California - Northern

Information: Neurodegenerative movement disorder group (PSP, CBD, MSA, etc.). Caregivers only. Contact Robin Riddle for more information.

Date: Every six weeks (call or e-mail for schedule)

Time: 5:00 - 7:00 pm

Location: Mimi's Cafe, 2208 Bridgepointe Parkway, San Mateo, CA 94404

Contact: Robin Riddle, 650-814-0848, rriddle@stanfordalumni.org

California - Los Angeles (Southern Counties of Los Angeles, Orange, Riverside, San Bernardino, Ventura, Santa Barbara, Kern, San Diego & Imperia)

Information: Group for patients and caregivers dealing with Atypical Parkinsonian Disorders like Progressive Supranuclear Palsy (PSP), Corticobasal Degeneration (CBD), Multiple System Atrophy (MSA) [Olivo-ponto-cerebellar Atrophy (OPCA), Striato-Nigral Degeneration (SND), Shy-Drager Syndrome (SDS)] and other neurodegenerative disease.

Date: 3rd Saturday of every month

Time: 1:30 - 3:30 pm

Location: Kaiser Permanente West Los Angeles Medical Center, 6041 Cadillac Avenue, Clinic Building, Basement Level, Classroom D, Los Angeles, CA 90034, 323 857-2000.

Directions/Parking: Entrance to the parking lot is either from Cadillac Avenue or La Cieniga Boulevard just blocks north of Venice Boulevard and the 10 Freeway. Security guards can help guide you to the meeting room.

Contact: Larry Schenker: atypical.parkinsonian.disorder@gmail.com, 310-441-1488

California – Orange County (Counties of Orange, Northern San Diego, Southern Los Angeles, Riverside, San Bernardino)

Information: Group for patients and caregivers dealing with Atypical Parkinsonian Disorders like Progressive Supranuclear Palsy (PSP), Corticobasal Degeneration (CBD), Multiple System Atrophy (MSA) [Olivo-ponto-cerebellar Atrophy (OPCA), Striato-Nigral Degeneration (SND), Shy-Drager Syndrome (SDS)] and other neurodegenerative disease.

Date: 1st Wednesday of every month

Time: 2:00 - 4:00 pm

Location: UCI Gottschalk Medical Plaza, One Medical Plaza Drive, 1st Floor Multispec Conference Room, Irvine CA 92697, 949 824-1264.

Contact: Larry Schenker: atypical.parkinsonian.disorder@gmail.com, 310 441-1488

Vera James (Orange County Facilitator): FVJAMES@aol.com, 909 598-1840



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California - San Diego (Counties of San Diego, Imperial, Southern Orange)

Information: Group for patients and caregivers dealing with Atypical Parkinsonian Disorders like Progressive Supranuclear Palsy (PSP), Corticobasal Degeneration (CBD), Multiple System Atrophy (MSA) [Olivoponto-cerebellar Atrophy (OPCA), Striato-Nigral Degeneration (SND), Shy-Drager Syndrome (SDS)] and other neurodegenerative disease.

Date: 1st Monday of every month

Time: 1:30 - 3:30 pm

Location: Coral Room (main level next to cafeteria), UCSD Thornton Hospital, 9300 Campus Point Drive, La Jolla, CA 92037, 858 657-7000

Directions/Parking: From the I-5: Exit on Genesee Avenue and go East. Turn right on Campus Point Drive. Thornton Hospital is located on the right.

From the I-805: Exit on La Jolla Village Drive/Miramar Road, and go West. Turn right on Genesee Avenue, then turn left on Campus Point Drive. Thornton Hospital is located on the right.

Contact/Coordinator: Larry Schenker, atypical.parkinsonian.disorder@gmail.com, 310-441-1488

Joyce Snell (San Diego Facilitator): joycesnell@san.rr.com; 858 456-1230

California – Sacramento

Information: Support group for persons affected by PSP, CBD, and MSA and their families and caregivers

Date: 2nd Saturday of each month

Time: 3:00pm – until finished

Location: location rotates each month; please contact the Rubenstein's for monthly information

Contact: Loren & Jodie Rubenstein, 916-704-6111, Irrjar@hotmail.com

Colorado - Denver/Englewood

Information: Neurodegenerative movement disorder group (MSA, PSP, CBD).

Date: 2nd Friday of each month

Time: 10:00 am - 12:00 pm

Location: Johnson Adult Day Center, 3444 South Emerson St., Englewood, CO 80113

Contact: Helenn Franzgrote, 303-789-9900, jhfranzgrote@comcast.net or

Deri Watroba, 303-663-9418, drwatroba@aol.com



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Florida – Southwest Florida

Information: This group is open to persons affected by PSP, CBD, MSA and related brain diseases including patients, caregivers, family members, etc.

Date: Saturday's each month

Time:

Location: Manor Care at Lely Palms, 6135 Rattlesnake Hammock Road, Naples, FL 34113

Contact: Cindy MacDonald, 239-353-3960 or 239-404-4429, hotrdh@hotmail.com

Florida – Southeast Florida

Information: This group is open to persons affected by PSP, CBD, MSA and related brain diseases including patients, caregivers, family members, etc.

Date: 2nd Saturday of each month starting March 13, 2010

Time: 2:00 - 4:00pm

Location: North Broward Medical Center, 201 E. Sample Road, Classrooms 7&8 (first floor), Deerfield Beach, FL 33064; 954-941-8300

Contact: Paul Freeman, 305-970-0805, freemanph@aol.com

Georgia – Atlanta

Information: This group is open to patients and caregivers living with atypical parkinsonism's, PSP, and CBD

Date: 2nd Saturday of each month (except May)

Time: 10:00 – 11:30am

Location: Wesley Woods Health Center, 3rd Floor Conference Room, 1841 Clifton Road, Atlanta, GA 30329

Contact: Lynn Ross, LMSW, 404-728-6300, slross@emory.edu

Illinois - Chicagoland

Information: PSP and CBD Support Group for Chicagoland area. Free and open to the public.

Date: First Saturday of every other month

Time: 1:30 - 3:30 pm

Location: The Abington of Glenview, Library, 3901 Glenview Road, Glenview, IL 60025

Contact: Darren Loveless, 847-729-0000, darrenloveless@yahoo.com



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Kentucky

Information: This group is geared toward support of PSP and CBD patients and their caregivers but welcomes others with other neurodegenerative diseases.

Date: 4th Wednesday of each month beginning March 24, 2010

Time: tbd

Location: University of Louisville, Center of Excellence in Corticobasal Degeneration

Contact: Todd S. Bryan, Program Manager, 502-561-3029, tsbrya01@louisville.edu

More information is available (and RSVPs can be sent) on Facebook at:

<http://www.facebook.com/event.php?eid=216646629952#!/pages/The-Center-of-Excellence-in-Corticobasal-Degeneration/247401763789> OR www.cbdsupport.blogspot.com

Maine

Information: This group is a support group for patients and caregivers dealing with atypical parkinson's diseases, including PSP, CBD, MSA, etc.

Date: Once a quarter on Saturdays. Call Janet for details.

Time: 1:00-3:00pm

Location: Contact Janet for information

Contact: Janet Edmunson, 207-799-1686, janet@janetedmunson.com

Maryland: Baltimore

Information: This group welcomes patients with PSP, CBD and other neurodegenerative diseases and their caregivers.

Date: Quarterly on Saturday's (contact Kate for meeting dates)

Time: 10:00am - 12:00pm

Location: Baltimore area locations (tbd)

Contact: Kate DeSantis, 410-785-7004, desantis@curepsp.org

Maryland: Anne Arundel County

Information: This group is open to patients with PSP, CBD and other neurodegenerative diseases and their caregivers.

Date: Sundays, every other month.

Time: 1:00 – 3:00 pm

Location: Kris Leigh Assisted Living Facility, 831 Ritchie Highway, Severna Park, MD

Contact: Kathy Orr, 410-798-6506, kathy_orr@verizon.net



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Massachusetts

Information: This group is a support group for patients and caregivers dealing with atypical parkinson's diseases, including PSP, CBD, MSA, etc.

Date: Once a quarter on Saturdays. Call Ann for details.

Time: 1:00-3:00 pm

Location: Lahey Clinic, Boston, MA

Contact: M. Ann Aversa, 617-872-8356, a.finigian@comcast.net

New Jersey – Northern

Information: This group will provide support and education to persons with PSP, CBD and related diseases and their families and caregivers.

Date: 4th Saturday of each month.

Time: 10:30am to 12:00pm

Location: Robert Wood John University Hospital (UMDNJ), Medical Education Building, Room 108-A, New Brunswick, NJ 08901

Contact: Dee Gozonsky, 609-918-0072, lgozo@aol.com

New York – NYC Metro Area (Counties of New York including New York City, Kings, Bronx, Richmond, Queens, Nassau, Suffolk, Westchester, Rockland; Counties of Connecticut: Fairfield)

Information: Group for patients, caregivers, family and friends affected by Atypical Parkinsonian Disorders like PSP, CBD, MSA/SDS, etc., and other neurodegenerative diseases.

Date: 3rd Saturday of each month (beginning January 16, 2010)

Time: 1:30 – 3:30pm

Location: North Shore University Hospital, Tower Conference Rooms, First Floor, 300 Community Drive, Manhasset, NY 11030, (516) 562-0100

Contact: Facilitator: Kara Holisher, 516-932-1696, kbhx2@optonline.net;
Harriet Feiner, 718-224-4654, hfeiner@nyc.rr.com.



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Ohio - Berea

Information: This group welcomes patients with PSP, CBD, MSA, Shy-Drager+Lewy Bodies and their caregivers, family and friends.

Date: 2nd Sunday of each month (unless a holiday)

Time: 1:00 - 3:00pm

Location: Southwest General Hospital, Room 15C (basement level), 18697 Bagley Road, Middleburg Heights, OH. Hospital is easy accessed from I-480, I-71 and the Ohio Turnpike. Free parking in garage in rear of hospital.

Contact: Pat Beekman, 440-234-0007, mombeekman@aol.com

Pennsylvania - Western/Pittsburgh North

Information: This group is a PSP/CBD support group.

Date: 3rd Thursday of the month

Time: 7:00 – 9:00 pm

Location: Dutilh United Methodist Church, 1270 Dutilh Road, Cranberry Township, PA 16066

Contact: Ruth Nulph, 724-287-8600, lnulph35@aol.com

Pennsylvania – Eastern/Philadelphia

Information: This group supports movement disorders.

Date: 2nd Saturday of every other month

Time: 10:00 am

Location: Penn Neurological Institute, 330 S. 9th Street, Philadelphia, PA 19107

Contact: Joellen Dembowski, 215-829-5071

South Carolina - (Northern and Southern North Carolina)

Information: This group supports patients and caregivers with PSP, CBD and related disorders.

Date: 3rd Saturday of each month

Time: 2:00 – 3:30 pm

Location: St. Philip Neri Catholic Church, Lou Kuchinic Ministry Building, Room 103, 292 Munn Road, Fort Mill, SC 29715.

Contact: Barbara Smith, 803-396-0963 (h) / 704-877-5940 (c),
barbandleon@comporium.net



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Texas - Houston

Information: This group is geared toward patients with PSP, CBD, MSA and LBD and their families

Date: 3rd Saturday of each month (except July and December)

Time: 1:00 pm

Location: Memorial Hermann Southwest Hospital, Learning Center B, Professional Building II, Houston, TX

Contact: Karen Kennemer, 281-358-2282, kmk1224@aol.com

Texas - Dallas

Information: Support group for PSP and CBD patients and caregivers

Date: 3rd Saturday of the month (except August)

Time: 1:00-3:00 pm

Location: Presbyterian Hospital, 8200 Walnut Lane, Dallas, TX 75231, Conference Room

Contact: Terry Peake, 214-348-2633, terrypeake@sbcglobal.net

Texas - Austin

Information: This group currently supports caregivers of PSP, CBD and MSA patients but accept other neurodegenerative disease caregivers as needed.

Date: 1st Saturday of each month

Time: 2:00 - 4:00 pm

Location: Georgetown Library (call for directions)

Contact: Kay Kitts, 512-591-7505, kkitts37@gmail.com

Vermont - Burlington

Information: Support group for caregivers of persons with Parkinson's with mild cognitive impairment and Parkinson's Plus syndromes (PSP, Shy Drager Syndrome, olivopontocerebellar atrophy, CBD, MSA, striatonigral degeneration, Parkinson's disease with ALS).

Date: Varies; call for details

Time: Varies; call for details

Location: Varies; call for details

Contact: Janice Clements, 802-862-7464, janclem25@gmail.com



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Washington - Spokane

Information: This group welcomes patients and caregivers with PSP and CBD but is open to supporting other neurodegenerative diseases as needed.

Date/Time/Location: determined as needed.

Contact: Mary Anne Memminger, 509-921-6645; Jim Barron, 509-332-6053 / 509-993-6656, jimcbarron@yahoo.com.

Washington - Seattle

Information: A PSP and CBD support group open to patients, caregivers, friends, etc. who have or had a person with PSP/CBD in their lives.

Location: Virginia Mason Medical Center

Date: Once a month on Mondays (typically the first Monday but may vary; call for details)

Time: 6:30 - 8:00 pm

Contact: Mary Beth Simiele, 206-290-5391, mary.simiele@vmmc.org

Canada - Kitchener, ON

Information: This group primarily supports caregivers, but patients may attend.

Date: Once a quarter on Saturday's (contact Tracy for meeting dates)

Time: 1:00 - 3:00 pm

Location: St. Mark's Lutheran Church, Kitchener, ON

Contact: Tracy Ellig, 519-570-0254, pspsupportincanada@hotmail.com

Canada - Toronto, ON

Information: This group is hosted by Parkinson Society of Canada – Central & Northern Ontario and is for care partners of PSP patients.

Location: 4211 Yonge Street, Suite 321, Toronto, ON

Date: Once a month (dates to be announced)

Time: 7:00 – 8:00pm

Contact: Sandie Jones, 416-227-3372 / 800-565-3000 x3372, sandie.jones@parkinson.ca

Australia

Information: This group provides support to PSP patients and caregivers.

Date: First Thursday of every other month (2010: February, April, June, August, October, December)

Time: 10:30am

Location: Parkinson's Victoria

Contact: Anne Mooney, damooney@bigpond.com



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Multiple System Atrophy/Shy-Drager Syndrome

The SDS/MSA Support Group

P.O. Box 279

Coupland, TX 78615

1-866-SDS-4999

shydrager@yahogroups.com

www.shy-drager.org



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CurePSP Online Support Groups

CurePSP sponsored online support groups allow participants the opportunity to interact with other patients, caregivers, and family members affected by PSP, CBD, MSA or related diseases by using their computer, telephone, or both. Below is a list of online support group meetings in which you may wish to participate. Each groups' schedule is posted directly on the CurePSP Support Network landing page.

PSP Patients

Meets the 2nd & 4th Monday's of each month at 8:00pm Eastern time

<https://www1.gotomeeting.com/register/575817233>

Facilitator - Kelley Pistacchio: kel925@cox.net

Facilitator - Jan Harrison: jan729@cox.net

PSP Spouses, Significant Others & Caregivers

Meets the 2nd & 4th Wednesday of each month at 8:00pm Eastern time AND the 2nd and 4th Tuesday of each month at 4:00pm Eastern time.

<https://www2.gotomeeting.com/register/882165194>

Facilitator - Larry Schenker: atypical.parkinsonian.disorder@gmail.com

Adult Children of PSP Patients (Not Residing with Parent)

Meets the 1st Wednesday of each month at 8:00pm Eastern time

<https://www2.gotomeeting.com/register/119178819>

Facilitator - Laurie Spindler: imthingone@yahoo.com

Non-Immediate Family Members of a PSP Patient

Meets the 2nd Monday of each month at 6:00pm Eastern time

<https://www1.gotomeeting.com/register/772227456>

Facilitator – Debra Brodsky: debra.brodsky@gmail.com

Facilitator – Lauren Brodsky: lbrodsky04@yahoo.com



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MSA Patients

Meets the 3rd Monday of each month at 8:00pm Eastern time

<https://www2.gotomeeting.com/register/759482131>

Facilitator – Gary Rose: gary.rose.wa@comcast.net

Facilitator – Vera James: fvjames@aol.com

MSA Spouses, Significant Others & Caregivers

Meets the 4th Monday of each month at 8:00pm Eastern time

<https://www2.gotomeeting.com/register/977578139>

Facilitator – Vera James: fvjames@aol.com

Facilitator - Judy Biedenham: jhbied@wowway.com

Adult Children of MSA Patients (Not Living with Parent)

Meets the 3rd Wednesday of each month at 8:00pm Eastern time

<https://www1.gotomeeting.com/register/219617433>

Facilitator - Sophie Harper: sh_cw_tainan@yahoo.com

Facilitator – Vera James: fvjames@aol.com

CBD Patients, Caregivers, Children & Family members

Meets the 3rd Tuesday of each month at 4:00pm Eastern time

<https://www1.gotomeeting.com/register/893287256>

Facilitator - Eileen Kamhi: eileen1948@hotmail.com



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Additional Online Support Resources

Online support resources allow you the chance to ask your specific questions to people and/or family members of others facing PSP, CBD, MSA or related disorders. You can also learn just by reading the postings of others. Below is a list of online support resources that you can join. *[Please note that some of the following groups (Yahoo Groups) are not affiliated with CurePSP, so CurePSP is not responsible for the content and postings of those groups.]*

- PSP & CBD through the CurePSP website: *<http://forum.psp.org/>*
- CBD: *http://health.groups.yahoo.com/group/cbgd_support/*
- MSA: *<http://health.groups.yahoo.com/group/shydrager/>*
- MSA: *<http://health.groups.yahoo.com/group/multiplesystematrophy>*
- PSP: *<http://health.groups.yahoo.com/group/pspinformation>*



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WE NEED YOU!

CurePSP continually seeks motivated individuals to start and facilitate support groups in their local area. Please consider sharing some of your time with others affected by PSP, CBD, MSA and related brain diseases by becoming a support group leader.

If you are interested, contact Richard Zyne, at 800-457-4777 or via e-mail at zyne@curepsp.org.

DISCLAIMER: The support groups, communicators and support group networks of the Foundation are provided for educational and informational purposes only ("Support Group Network"). This Support Group Network is not a substitute in any way for medical treatment, advice, diagnosis or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have learned from the Support Group Network.

The Foundation does not recommend or endorse any specific tests, treatments, physicians, products, procedures, opinions, or other information that may be mentioned at the Support Group Network. Reliance on any information provided by the Foundation, Foundation employees, others in the Support Group Network at the invitation of the Foundation or other visitors to the Support Group Network is solely at your own risk. You should not rely on information you receive from or through the Support Group Network for any personal, medical or health decision, but should consult with a qualified professional for specific information suited to your case.

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